

InTouch Newsletter

September 2022

Pump for Parkinson's raises funds for nurse

On Thursday 29 September the Bailey Centre Liberty Service Station will contribute 10 cents per every litre of fuel sold to support the Parkinson's Coffs Harbour Nurses Fund.

Local delivery firm PK Express Transport has also committed to contribute an additional 5 cents per litre sold. The fundraising effort will kick off at 12.01am and run for a full 24 hours.

This year for the first time, a third donor has joined this fundraising initiative. CHES Connect is a not-for-profit human service organisation that provides a range of specialist Employment, NDIS and Workplace Wellbeing supports. CHES has donated \$300 to the fundraiser.

Service station customers who 'Pump for Parkinson's' will be helping to raise funds to maintain the services of a Parkinson's Specialist Nurse based in the Mid North Coast Local Health District in Coffs Harbour.

This nursing position is co-funded by the Local Health District and Parkinson's NSW. Fundraising goes towards the Parkinson's NSW portion of the funding for this important role.

The fundraiser is an initiative of the Coffs Harbour Parkinson's Support Groups and the Bailey Centre Liberty Service Station.

"We've been doing this for six years now and it's always a pleasure to help out where we can for this very worthy cause. We are looking forward to many more years, said Paul Amos from the Bailey Centre Liberty Service Station.

"People living with Parkinson's – which has a huge effect on their quality of life – are under-served in regional communities like ours. Parkinson's Specialist Nurses are their best connection to advice and support, and we are lucky to have one here."

David Strickland of PK Express Transport agreed, saying: "We have a great community here in Coffs and we take care of our own. This fundraiser was the perfect opportunity for us to make a contribution to our hometown – especially since people living with Parkinson's need specialised local support to manage their disease."

Five podcasts for people living with Parkinson's

Whether you're looking for a beginner's guide to Parkinson's or expert insights on a range of symptoms, find out what these five podcasts recommended by [Parkinson's Life](#) have to offer

2 Parkies in a Pod

Sports journalist and broadcaster Dave Clarke partners with his friend Dave Kuhan to discuss the ins and outs of Parkinson's, drawing on their twenty collective years of living with the condition. Including a host of guests throughout the series, episode one offers a 'beginner's guide' to living well with Parkinson's – with the aim of helping listeners understand what to expect.

You, Me and PD

Born from the relationship between technology professional Jeremy Likness, who was diagnosed with young onset Parkinson's in 2020, and his wife Doreen – *You, Me and PD* is a conversational podcast which looks at their shared approach to Parkinson's. Topics include nutrition, exercise, faith and coping with grief.

The Parkinson's Experience podcast

Sheryl Lowenhar, who lives with Parkinson's, talks about her personal experiences in this podcast. Sharing the viewpoint of a patient, she explores an array of topics including mental health, travel, therapies for people with Parkinson's and research developments into areas like gene therapy.

On Time

Co-hosted by Brian Grant – former NBA player and founder of the Brian Grant Foundation – and writer and Parkinson's advocate [Heather Kennedy](#), this podcast offers a candid look at daily life with the condition including perspectives on parenting, dating and maintaining a healthy lifestyle.

The Parkinson's Life podcast

Aiming to offer a voice to people living with the condition, this podcast brings together patients and experts from around the world to discuss diverse issues – from the research gap around women and Parkinson's to the challenges related to impulsive behaviours. Explore [all the episodes](#).

Proposal to provide more Australians with access to Commonwealth Seniors Health Card

Legislation due to take effect on 20 September 2022 (if passed) will enable more Australians to access the Commonwealth Seniors Health Card.

This will provide medical and pharmaceutical concessions for those who have reached age pension or veteran pension age.

Pending the passage of legislation, the income limits for the Commonwealth Seniors Health Card will increase from \$57,761 to \$90,000 for singles and from \$92,416 to \$144,000 for couples (combined).

More than 44,000 newly eligible CSHC holders are expected to benefit within the first year of implementation. This is projected to increase to an additional 52,000 card holders by 2026-27.

Minister for Social Services Amanda Rishworth said the Social Services and Other Legislation Amendment (Lifting the Income Limit for the Commonwealth Seniors Health Card) Bill will help older Australians when they needed it most.

Older Australians can use their Commonwealth Seniors Health Card to access cheaper medicines under the Pharmaceutical Benefits Scheme (PBS), bulk billed doctor visits (at the discretion of the provider), and the lower thresholds of the PBS and Extended Medicare safety nets.

Eligible Australians can apply for a Commonwealth Seniors Health Card on the [Services Australia website](#).

***Step up for Parkinson's* campaign raises \$125,135**

The concept of the *Step up for Parkinson's* fundraising campaign in May was simple and flexible but delivered multiple benefits. People were invited to get active and raise funds for people living with Parkinson's.

Who they raised funds for, how and where they got active, with whom, and over what times or distances was entirely up to the individual.

As a result, not only did the campaign raise \$125,135 to fund services for the NSW Parkinson's community, but it also brought together friends, family, pets, and communities – and encouraged a healthy and active lifestyle.

A total of 241 people registered for the fundraiser and they attracted 1634 donations.

Several Support Groups entered as teams, including:

- Chatswood – Raised \$2052
- Blacktown – \$1870
- Port Macquarie – \$448
- St George Sutherland – \$347
- Calvary Kogarah – \$53
- Newcastle – \$53

As the highest fundraising Support Group, Chatswood won a \$500 gift card.

The Campaign also included a digital honour wall that allowed participants to share why they were taking part in *Step Up for Parkinson's*. There were some touching stories on the *I'm stepping up for...* page.

Wilma: “I’m stepping up as my husband has recently been diagnosed with Parkinson’s.”

Mick: “My Dad, his brother, and their father before them all had Parkinson's. I also know people now who have Parkinson's. I'm Stepping Up to raise funds so present and future sufferers of Parkinson's can have a better outlook than those who have gone before.”

Therese: “Little Penny is a 7-week-old miniature foxy and she is stepping up with me to raise funds for Parkinson’s NSW. These funds will be used to help people with Parkinson’s live full and happy lives.”

Jean: “I’m stepping up in memory of my beautiful mum.”

Read more stories and tributes [here](#).

Thank you to everyone who participated and sponsored participants in this fundraising campaign. It will be back again in 2023.

Tongue Tied

One of the less discussed symptoms of Parkinson’s is Dysphagia. Dysphagia is the term for swallowing difficulty.

Parkinson’s affects the muscles and nerves responsible for the mechanics of swallowing and this can have a great impact on your quality of life.

Some of the symptoms of Dysphagia are.

- Choking when eating
- Coughing or gagging when swallowing
- Drooling
- Reflux and heartburn
- Hoarseness
- Regurgitation of food
- Difficulty chewing and starting to swallow
- Inability to control saliva production.
- Recurring pneumonia

Many people become frustrated and embarrassed and subsequently isolate themselves from social events like dinner or eating out with friends or family.

Dysphagia can also lead to malnutrition, dehydration, and aspiration (when food or liquid goes down the wrong pipe). Aspiration is often silent (no coughing or choking) and can lead to aspirational pneumonia – the leading cause of death in Parkinson’s.

Your doctor can help improve swallowing with medication adjustments but it is also wise to visit a Speech Pathologist for individual treatment and exercises. The specific exercises will depend on your swallowing problem.

For example, if you have a problem with the first phase of swallowing, before the food leaves your mouth, tongue exercises may help. Different exercises will be recommended if your problem lies in the later stages of swallowing.

Following are some easy tongue strengthening exercises you can do at any time.

1. Stretch your tongue out of your mouth. Hold this position for 5 counts. Repeat 5 times.
2. With your mouth open, stretch your tongue out and move it from side to side – first to the left side and then to the right side of your mouth. Repeat 5 times each side, holding for a count of 5 each time.
3. Open your mouth as wide as you can, and then try to touch the tip of your tongue to your upper teeth or to the front of the palate. Do this for 3 to 5 seconds. Repeat 5 to 10 times.
4. With your mouth closed, move your tongue in a circle on the inner surfaces of your lips, inside your mouth. Do this first in a clockwise direction. Repeat 3 times. Then do this in an anti-clockwise direction. Repeat 3 times.
5. Close the tip of your tongue to your palate above and hold for 5 counts. Repeat 5 times.
6. Press the tip of your tongue inside of each cheek. Repeat this exercise 5 to 10 times.

Don't let dysphasia effect your quality of life and your health. Speak with your Parkinson's health professional about exercises to slow or prevent dysphasia as a possible symptom of your Parkinson's journey.

Sources

<https://www.doctorpareshdoshi.com/parkinsons-disease/tongue-exercise-for-parkinsons-disease/>
<https://neurologicalsurgery.in/voice-exercises-for-parkinsons-disease/>
<https://www.hopkinsmedicine.org/health/treatment-tests-and-therapies/swallowing-exercises-how-to-do-tonguestrengthening-exercises>
<https://swallowingdisorderfoundation.com/oral-swallowing-exercises/>
<https://napacenter.org/swallow-strengthening-exercises/>
<https://www.parkinson.org/Understanding-Parkinsons/Symptoms/Non-Movement-Symptoms/Speech-and-Swallowing-Problems>
<https://www.medicalnewstoday.com/articles/177473#symptoms>

How to track your medications on an iPhone

The Health application on your Apple iPhone gains fresh capabilities with the iOS 16 software update that will be valuable for many people living with Parkinson's.

The major new feature is the ability to track medications on your iPhone (including vitamins and supplements as well).

The Health application adds Medications, allowing users to conveniently build and manage a medications list, create schedules and reminders, and track their medications, vitamins, or supplements.

Along with all that, the feature tells users about potential interactions between medications and it's possible to connect with healthcare providers to see a list of past medications, get future updates, or add items to your schedule.

Here is a quick guide to tracking medications on iPhone: iOS 16 software.

Running iOS 16 on your iPhone, open the **Health app**

1. Choose the **Browse tab** in the bottom right corner
2. Tap **Medications**, then choose **Add a Medication**
3. Type in your medication details
4. Follow the prompts to set reminders and more
5. Head back to the Health app > Browse tab > Medications any time to log what you've taken and more

[Here's how it looks to track medications on iPhone](#)